

A Guide to Being a Caregiver

Caring for a loved one with Alzheimer's is one of the biggest commitments one person can make to another. Alzheimer's is a disease that can span up to 20 years. For the caregiver, this period will be emotionally, physically and financially challenging.

Legal and Financial Planning

Legal and financial planning should be one of the first steps that a caregiver takes once the diagnosis has been made. Persons with Alzheimer's may have the capacity to manage their own legal and financial affairs right now, but as the disease advances, they will need to rely on others to act in their best interest. This transition will be difficult, however advance planning allows persons with the disease and their families to make decisions together for what may come.

Legal Matters

Clearly written legal documents that outline your loved one's wishes and decisions are essential. These documents can authorize another person to make health care and financial decisions, including plans for long-term care coverage. If the person with Alzheimer's has the legal capacity — the level of mental functioning necessary to sign official documents — he or she should actively participate in legal planning. It is essential that you obtain legal advice and services from an attorney. If your loved one is 65 years or older, consider hiring an attorney who practices elder law, a specialized area of law focusing on issues that typically affect older adults. As you plan for the future, ask the attorney about the following documents:

- A **power of attorney** gives a person with Alzheimer's (the *principal*) an opportunity to authorize an agent (usually a trusted family member or friend) to make legal decisions when he or she is no longer competent.
- A **power of attorney for health care** appoints an agent to make all decisions regarding health care, including choices regarding health care providers, medical treatment, and, in the later stages of the disease, end-of-life decisions
- A **living will** allows the person with Alzheimer's disease to express his or her decision on the use of artificial life support systems.
- **Living trusts** enables a person (the *grantor* or *trustor*) to create a trust and appoint himself or herself or someone else as trustee (usually an individual or bank) to carefully invest and manage trust assets once the grantor is no longer able to manage finances because of cognitive impairment.
- A **will** is a document created by an individual that names an *executor* (the person who will manage the estate) and *beneficiaries* (those who will receive the estate at the time of the person's death).

A caregiver of an individual who no longer has legal capacity to execute powers of attorney or trusts may have to become that individual's guardian or conservator. A guardian/conservator, appointed by a court, has the legal authority to make decisions regarding the care and custody of the person with Alzheimer's.

Take a Hard Look at Finances

The first step in planning how to pay for your loved one's future medical and living expenses is to start with an honest look at your family's current financial situation, as well as that of the person with Alzheimer's.

- Assemble the person's assets by locating such financial documents as bond certificates, bank account statements, real estate deeds and insurance policies

- Work with a qualified adviser, such as a financial planner, an estate planning attorney, or an accountant, to coordinate financial strategies and investments, locate potential financial sources, and identify tax deductions
- Identify expenses you may encounter, including ongoing medical treatments, prescription medicines, care services, and consumable products, such as incontinence supplies.

The costs for caring for a person with Alzheimer's are considerably high, averaging close to \$175,000 throughout the span of the disease. You may be concerned about depleting all of your resources — and those of your loved ones — to pay for care. To help offset these costs, you may utilize the many resources available including:

- **Healthcare insurance**
Health care insurance may include private, retiree and government-funded insurance.
- **Medicare**
Medicare is a federal health insurance program generally for people age 65 or older that are receiving Social Security retirement benefits. Medicare covers inpatient hospital care and a portion of the doctor's fees and other medical expenses. There are specific eligibility requirements in order for a person to receive assistance from this program. Medicare covers some, but not all, of the services a person with Alzheimer's disease may require. Applications for Medicare may be sent to a local Social Security office.
- **Medigap**
Medicare coverage can be supplemented with Medigap, a private insurance that covers co-payments and deductibles required by Medicare. The more expensive policies may cover prescription drugs.
- **Medicare HMO (Medicare Managed Care)**
Medicare HMO offers some additional benefits and less paperwork in exchanged for restrictions on choices of hospitals, doctors, and other professionals. Most Medicare HMOs cover nursing home and home health care for limited periods only under special circumstances.
- **Medicaid**
Because Medicaid is a federal program typically administered by each state's welfare agency, eligibility and benefits vary from state to state. The program is typically administered by a state welfare agency. Medicaid covers all or a portion of nursing home costs. A person with Alzheimer's can qualify for long-term care only if he has minimal income and cash assets.
- **Retirement benefits**
Retirement benefits that provide critical financial resources include retirement plans, individual retirement accounts (IRAs), annuities, and Social Security.
- **Personal savings, investments, and property**
Investment assets (stocks and bonds, savings accounts, real estate, etc.) and personal property (jewelry and artwork) can be sources of income. Money from the sale of a home can be invested, or a reverse mortgage can be taken out on a home.
- **Tax credits**
If you claim your loved one as a dependent under federal tax regulations, you may be eligible for medical expense deductions and dependent care credits. For more

information on tax issues, contact the Greater Pittsburgh chapter at **1(800) 652-3370** or **(412) 261-5040**.

- **Social Security disability**

This program assists wage earners under 65 who can no longer work because they are disabled. The applicant must have worked a minimum of five nonconsecutive years in the past ten years. A diagnosis of Alzheimer's does not establish disability status. You must prove that the person with Alzheimer's is unable to work by submitting physician statements and other documentation to your local Social Security office.

- **Supplemental security income**

This program guarantees a minimum monthly income to persons who are age 65 or over, disabled, or blind and have limited income and assets. To qualify as disabled, persons with Alzheimer's disease must be proven to be unemployable. It is important to apply soon after a diagnosis is made because payments ordinarily begin with the date of application or eligibility.

For more information on legal and financial issues, click here to contact the Greater Pittsburgh chapter.

Day-to Day Care

Planning Activities

Daily activities can mean the difference between feeling loved and needed versus feeling unloved and helpless. When planning activities and daily tasks to help the person with Alzheimer's organize their day, you must think about the skills and abilities the person with Alzheimer's has. What does the person enjoy doing?

Does the person begin activities without direction? Does the person have physical problems?

Each activity should focus on enjoyment, not on achievement. Determine the best time for the activity and make it a regular part of the day. Your approach should be supportive – be flexible, patient and stress involvement. While supervising the activity, help the person remain as independent as possible, and simplify instructions. The environment should be safe and have minimal distractions that could frighten or confuse the person. Whenever possible, change your surroundings to further encourage activities.

Hygiene and Personal Care

People with Alzheimer's disease may need help with grooming and hygiene. The need for assistance in this area can be very difficult for them to understand, because it signifies a loss of independence and privacy. As a caregiver, you may also feel uncomfortable interfering with one's privacy.

The following are tips designed to assist the caregiver with personal care issues:

Bathing

- Do everything you can in advance to make the process easier, such as increasing the room temperature and having bath towels nearby.
- Make the person feel in control. Involve and coach him or her through each step of the process. You may need to experiment to determine if the individual prefers showers or tub baths and what time of day is best.

- Create a safe and pleasing atmosphere. Place non-slip adhesives on the floor surface and grab bars in the bathtub to prevent falls. Test water temperatures in advance to prevent burns.
- Respect the person's dignity. Some individuals may be self-conscious about their nakedness. Allowing the person to hold a towel in front of the body, both in and out of the shower, may ease anxiety.
- Don't worry about the frequency of bathing. Sponge baths can be effective between showers or baths.

Toileting

It is common for persons with Alzheimer's disease to experience loss of bladder and/or bowel control. This can be caused by many factors, including medications, stress, a physical condition, the environment, and the person's clothing. If incontinence is a new problem, consult your doctor to rule out potential causes such as a urinary tract infection, weak pelvic muscles, or medications.

Dental Care

Good oral hygiene can be a challenge for individuals with Alzheimer's. Brushing is sometimes difficult due to the individual's inability to understand and accept assistance from others. To help the individual, provide short and simple instructions. "Brush your teeth" may be too difficult. Instead try: "Hold your toothbrush" or "Put paste on the brush." Use a mirroring technique by holding a brush and show the individual how to brush his or her teeth. Finally, monitor daily oral care.

Dressing

Physical appearance contributes to everyone's sense of self-esteem. Clothing can be a form of self-expression, so it's important to consider the person's tastes and dislikes. To help the person with dressing, remember to simplify choices and choose comfortable clothing. Be flexible and organized – layout clothing whenever possible.

With all personal care activities, it is important to incorporate the individual's past routine whenever possible into the current one.

Communicating Effectively

People with Alzheimer's often find it difficult to express themselves and understand others. They may have difficulty finding the right words or experience difficulty organizing words logically. Often individuals speak less often and rely on non-verbal gestures.

Tips for Enhancing Your Communication:

- Maintain eye contact and show that you are listening and trying to understand what is being said
- Encourage the person to continue to express thoughts even if he or she is having difficulty
- Be careful not to interrupt and avoid criticizing, correcting, and arguing
- Be calm and supportive, and use a gentle tone of voice
- Use positive, friendly facial expressions
- Always approach the person from the front, identify yourself and address him or her by name
- Speak slowly and clearly
- Use short, simple, and familiar words
- Break tasks and instructions into clear, simple steps
- Avoid using pronouns and identify people by their names

- Don't talk about the person as if he or she wasn't there
- Have patience, flexibility and understanding

Understanding Changing Behaviors

Alzheimer's can cause a person to exhibit unusual and unpredictable behaviors, including:

- Severe mood swings
- Verbal or physical aggression
- Paranoia
- Hallucinations
- Anxiety
- Agitation
- Combativeness
- Wandering
- Incontinence
- Sleeplessness

These changes can lead to frustration and tension, particularly between persons with Alzheimer's and their caregivers. It is important to remember that the person is not acting this way on purpose. Changes in behavior can be caused by:

- Physical discomfort caused by an illness or medications
- Over-stimulation from a loud or overactive environment
- Inability to recognize familiar places, faces, or things
- Difficulty completing simple tasks or activities
- Inability to communicate effectively

Tips for Dealing with Challenging Behaviors:

- Stay calm and be understanding
- Be patient and flexible
- Don't argue or try to convince the person
- Acknowledge requests and respond to them
- Try not to take behaviors personally
- Accept the behavior as a reality of the disease and try to work through it

It is important to identify the cause of the challenging behavior and consider possible solutions:

Identify and examine the behavior

- What was the undesirable behavior? Is it harmful to the individual or others?
- What happened before the behavior occurred?
- Did something trigger the behavior?

Explore potential solutions

- Is there something the person needs or wants?
- Can you change the surroundings? Is the area noisy or crowded? Is the room well lit?
- Are you responding in a calm, supportive way?

Try different responses in the future

- Did your response help?
- Do you need to explore other potential causes and solutions? If so, what can you do differently?

Coping with Depression

Depression is a common cause of "reversible" dementia in older adults. Depression is four times more likely to strike those over age 65 than younger individuals. It is found in 20 percent of persons with Alzheimer's disease, in up to 50 percent of Alzheimer caregivers,

and in 15 percent of adults over age 65. Sadly, most people never get help for this treatable illness.

Recognizing depression in people with dementia

Persons with depression may lose interest or pleasure in activities that were once fulfilling, have difficulty concentrating, or experience feelings of hopelessness and worthlessness. They may exhibit such physical symptoms as changes in appetite, weight, energy and sleeping patterns.

Those with Alzheimer's disease commonly exhibit symptoms of depression in the early stages of the disease, while they are still aware. Because depression and dementia share common symptoms, the two are sometimes confused, with the result that depression often goes untreated in persons with Alzheimer's disease. Alzheimer symptoms, however, are more progressive than the symptoms of depression and include profound memory loss. While their depression can be treated through medications, the cognitive abilities of persons with dementia will continue to decline.

If symptoms of depression are present, it is important for you to obtain a complete medical evaluation to rule out any other physical causes. Medications or an unrecognized disorder may cause depression. If there are no other underlying causes, consult a psychiatrist or geriatric psychiatrist, which specializes in recognizing and treating depression in older adults.

Safety

When caring for an individual with Alzheimer's disease at home, safety and accessibility are important concerns. Here are some simple steps you can take to make the home safe for the person with Alzheimer's:

- Lock or disguise hazardous areas
- Install door locks out of sight
- Use special safety devices, such as child-proof locks and door knobs, to limit access to places where knives, appliances, equipment, and cleaning fluids are stored
- Diffuse bright light by removing or covering mirrors and glass-top furniture, and cover windows with blinds, shades, or sheer draperies
- Add extra lighting in entries, outside landings, areas between rooms, stairways, and bathrooms because changes in levels of light can be disorienting
- Place contrasting colored rugs in front of doors or steps to help the individual anticipate staircases and room entrances
- Monitor the temperature of water faucets and food because the person may have a decreased sensitivity to temperature
- Install walk-in showers, grab bars, and decals to slippery surfaces in the bathroom to prevent falls
- Supervise the person in taking prescription and over-the-counter medications
- Limit the use of certain appliances and equipment such as mixers, grills, knives, and lawnmowers
- Supervise smoking and alcohol consumption
- Remove objects, such as magazine racks, coffee tables, and floor lamps, to create safe wandering areas and reduce the possibility of injury
- Clean out the refrigerator regularly and discard inedible food

In the Event of an Emergency

- Keep a list of emergency phone numbers and addresses for local police and fire departments, hospitals and poison control help lines
- Check fire extinguishers and smoke alarms, and conduct fire drills regularly

- If the person with Alzheimer's tends to wander, enroll him or her in the *Safe Return Program*, a nationwide system designed to identify, locate and return to safety persons who are memory impaired (link to II-B-2)

Late-Stage Care

Comfort, dignity, and respect — these are important words for caregivers to remember in ensuring quality of life during the late-stage of Alzheimer's disease. At this point in the disease process, people typically lose the ability to talk and walk and experience difficulties with eating. Families and care providers play a critical role in making tough decisions that ultimately respect the person's end-of-life wishes and at the same time maintain the person's dignity and comfort.

Advance Directives

People with Alzheimer's have the legal right to limit or forgo medical or life-sustaining treatment, including the use of mechanical ventilators, cardiopulmonary resuscitation, antibiotics and artificial nutrition and hydration. These wishes can be expressed through advance directives. Two common forms of advance directives are a living will and a durable power of attorney for health care.

Family members should not equate the refusal or withdrawal of treatment, including treatment for life-threatening illnesses (infections, hemorrhaging, heart attacks, etc.) as euthanasia or assisted suicide. In fact, aggressive medical treatment may feel like torture to an individual who is in unfamiliar surroundings and does not understand the intentions of the care providers.

If there are no advance directives in place, families and care providers should try to make decisions consistent with what they think the individual's wishes would have been. Typically, nursing homes and hospitals have ethics committees that can facilitate the decision-making process if there is a conflict between family members or with the care provider.

Artificial Nutrition and Hydration

People with Alzheimer's may also refuse to eat and drink. Such cases should be evaluated to make sure that they are not due to conditions, such as constipation, kidney failure, nausea and fluid and electrolyte imbalance, that could be reversed with medications.

Many families and care providers believe that it is appropriate to do everything in their power to get the person to eat or drink. The use of feeding tubes and intravenous (IV) hydration is often assumed to prolong life when in fact it could be lengthening the dying process. In addition, if these artificial means are used, families will eventually be faced with the tough decision about whether or not to withdraw such treatment.

Treating Infections

Pneumonia and urinary tract infections are common in the last stage of Alzheimer's. The person's advance directive should indicate whether preventive measures such as pneumonia vaccines and antibiotics might be used. If the Alzheimer patient does not wish to receive these, care providers can use medications to reduce pain and make the person more comfortable.

If the patient cannot talk, it is important to look for behavioral clues such as depressive or psychotic symptoms, anxiety, and sleep and activity disturbances that may indicate he or she is experiencing pain.

Restraints

Restraints may be used in long-term care settings and hospitals as a means to control Alzheimer-related behavior problems such as wandering, agitation, and combativeness. They are also used to prevent patients who are receiving artificial nutrition from pulling out the feeding tube. Although restraints are intended to protect the safety of the patient, their use can cause harm as well as jeopardize the individual's independence and dignity. Physical restraints restrict the person's ability to move and, as a result, can cause incontinence, loss of muscle tone; pressure sores, depression, and decreased appetite.

People with Alzheimer's have the right to receive care without the use of physical or chemical restraints that are not needed to treat a medical condition. Care providers have an obligation to try alternatives to restraints, such as diversions for aggressive behavior or safe places to wander.

Hospice Care

People with Alzheimer's disease will likely be in and out of nursing homes and hospitals as the disease advances. One unique care option is hospice. The underlying philosophy of hospice focuses on quality and dignity by providing comfort, care and support services for people with terminal illnesses and their families. Hospice places an emphasis on maximizing patient comfort and providing counseling and bereavement services to the family before and after their loved one dies. To qualify for hospice benefits under Medicare, a physician must diagnosis the person with Alzheimer's disease as having less than six months to live.

Reach out for Support

It is important for caregivers to seek support during this difficult stage of the disease. Contact the Greater Pittsburgh chapter at **1(800) 652-3370** or **(412) 261-5040** to talk to a Help Line Specialist.